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ABSTRACT

In this paper, the author, who identifies himself as HIV positive, discusses his work as a counselor and advocate for people with AIDS. Background information on AIDS, from the first reported case in 1981 to current treatments, is provided. The use of revitalization counseling with AIDS patients, that is counseling that brings new life to an individual, is discussed. Counselors who work with AIDS patients are encouraged to use life-affirming, motivational methods that will help clients reach their goals, and therefore live longer. The lack of services available for AIDS patients, the stigmas placed by society on AIDS patients, and employment discrimination are some of the reasons why the need exists for advocacy. The author discusses how, through his own experiences as an advocate, he has been able to educate others who have as a result of these encounters changed policies to be nondiscriminatory, learned more about law, and become more confident in his advocacy abilities. This paper suggests that through advocacy, counselors can aid their clients in becoming empowered to help themselves and others, and thus counselors enhance their own effectiveness as practitioners and human beings. (MKA)

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Chapter Thirteen

Advocacy for People with HIV/AIDS

John Cebuhar

I have been intimately involved with HIV/AIDS since 1988, when I began counseling heroin addicts in a methadone maintenance setting in Chicago. I, myself, have lived with HIV infection since my own diagnosis in 1989. I share this with you so that you will know that I have had to become a strong advocate for myself as well as for others. My own diagnosis and my work with hundreds of People with HIV and AIDS have markedly changed both my counseling style and my philosophy regarding advocacy.

Background

The first cases of Acquired Immune Deficiency Syndrome (AIDS) were reported by a Los Angeles physician in 1981, when he noted a specific and deadly form of pneumonia that soon proved fatal to the two young, homosexual males who had been infected. In 1981, the mortality rate for AIDS from time of infection until death was approximately 20 months, with major incapacitation and debilitation present from early in the onset of the disease. Methods for detection of the HIV virus were not available until 1985. The first effective medication, Retrovir (AZT), was introduced in 1986. Newer classes of drugs were introduced in 1995 and 1996. When the "AIDS Drug Cocktail" was introduced in 1996, the Centers for Disease Control and Prevention noted a marked decline in the mortality rate from HIV infection. The drug cocktail is a combination of one or more drugs from at least two of the three classes of drugs that work in different ways to inhibit the reproduction of HIV. The new drug combinations do not afford a cure, nor are the combinations effective across the entire spectrum of HIV-infected individuals. This spectrum has broadened beyond men who have unprotected sex with men, injection drug

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users and their partners, and offspring born to HIV-infected mothers. HIV infection has spread to the heterosexual population at an alarming rate, especially in communities of color such as the African-American and Hispanic populations. AIDS remains a leading cause of death among adolescents and young adults.

Successful eradication of AIDS has yet to be realized, but the disease is now considered by many virologists to be difficult to control but controllable, at least for the present time. How long the new classes of drugs will remain effective is not known. What is known is that HIV is able to mutate to new strains rapidly, that the new drugs do not work with all people, and that both the drug side-effects and the dosing schedule can often lead to treatment failure. Prevention of HIV infection through abstinence or safer sexual and drug use practice remains an integral aspect of disease containment.

No cure for HIV/AIDS exists, and a cure may never be realized. Medical experts have switched from a strategy of developing a "magic bullet" to kill the retrovirus to developing a variety of different classes of drugs that act on different parts of the retrovirus in order to inhibit viral reproduction. Pharmacologists have also worked on developing medications that can effectively combat the myriad of diseases that can attack the body once immune-compromise has been realized. Diseases associated with AIDS include leukemia; cancers; tuberculosis (both pulmonary and organ and bone related varieties); Cytomegalovirus, which destroys eyesight; pneumonia and other respiratory illnesses; wasting syndrome; muscle-mass loss; dementia; neuropathy and other neural damage such as epilepsy and other seizure disorders; severe fatigue; depression; anorexia; heart, liver, and kidney disease and failure; anemia; and memory and motor-function problems brought about by organisms that attack the brain. AIDS medical experts are attempting to develop methods to rebuild the immune system that has been partially destroyed or completely impacted by HIV infection. Finally, the medical and pharmaceutical communities must develop new medications to combat the myriad side-effects associated with the medications taken to combat the primary infection of HIV. The side effects of the drugs can be as trying and difficult to manage as the disease itself.

Counseling People with AIDS

When I first began my work with People with AIDS, I had the mistaken concept that my counseling approach would closely

follow models developed for death and dying. I quickly learned, however, that this would not be the driving force of my practice. I now offer a new term for my counseling practice with People with AIDS: revitalization counseling. That is, counseling that brings new life to an individual.

The tasks of the client who is infected with HIV continue to be life tasks, and it is only through successful realization of these life tasks that a client can, when he or she chooses and if and when it is appropriate, initiate life-closure processes. If you are a counselor who wishes to work with People with AIDS or other life-threatening illnesses, you should put away your books on death and dying, estate planning, medical powers-of-attorney and medical directives. Reach instead for life-affirming, motivational methods that can help your clients reach their goals. Your clients, like all of us, will continue to have goals until they no longer live. The listening skills that you have honed through practice will serve as an excellent basis for counseling because they will enable your clients to teach you what it is like to live with a catastrophic illness and potential death. Someday, you too will need this learning for your own developmental process of living and dying. This process of discovery can be enlightening and exciting for you as a counselor, as well as for your clients. Your connection with your clients will also increase your awareness that advocacy skills need to be part of your repertoire.

The Need for Advocacy

Our social service systems and entitlement programs are bureaucratic, difficult to access, and not designed to handle the needs of the terminally ill. Social Security Disability or Supplemental Security Income can take years to access. Housing entitlement programs such as Section 8 have waiting lists of up to ten years. Pharmaceutical assistance programs to pay for basic medications for AIDS (which can run as high as $2,000-$3,000 per month) have spending caps and are often closed. Food stamp assistance is available to only the most indigent. Public Assistance is a nightmare and requires a total spend-down of all assets before any entitlement. Assisted living programs for People with AIDS have waiting lists. People who have a history of substance abuse may be denied services until they have two years of sobriety. All too often, people with AIDS become homeless and join our other unintitled, faceless, thrown-away citizens who must scurry to survive. Then, accessing services becomes even more difficult

because the individual has no permanent address. The client now has no way to maintain regular hygiene and no assistance with a difficult drug regimen of pills every eight hours. The individual's medications may be stolen, confiscated, or simply lost as he or she struggles to survive.

AIDS stigmatizes. AIDS discrimination exists in housing, in employment, in social-service access, in medical care, and in the very fabric of a society that chooses to blame the individual for his or her illness. Just at the time when the individual is most in need of nurturing and solace, it is ripped away. He or she is sent out of the community as a shunned individual to face life alone. If the client at this stage adapts or reverts to coping mechanisms such as drugs and alcohol, we use that as further proof of the righteousness of our inhumanity.

The Americans With Disabilities Act should serve as a framework for all of our talented individuals who, regardless of their physical or mental affliction, have a right to employment that will utilize their talents. We know that we are not all created equal in our talents and abilities and we know that we do not always stay equal in our ability to perform our work in a uniform manner. We also know, however, that each of us has some special gift or talent that is needed by our society. Providing for reasonable accommodations for those with special needs gives us the privilege of sharing in the talents of these people. Both sides benefit from this equation, as people are returned to situations in which they can be fruitful and productive members of society.

Although the federal government has passed the Americans With Disabilities Act (ADA), employment discrimination continues to exist. The ADA was rather vague in its intent and the real law is being litigated through court action. The agency charged with handling ADA complaints, the Equal Employment Opportunity Commission, has been downsized and already must handle all racial, age and other discrimination matters under other federal civil rights legislation. A complaint can take as long as two years, at which time a client is then given a right to sue letter and must pursue his or her case through federal court at his or her own expense. Because of Washington politics, the federal court has suffered a severe shortage of judicial appointments and thus a case can linger in the courts for years. Bear in mind that your elected officials have created this backlog and that the wronged party may not live to see justice!

Local, state, and federal governments all play roles in these problems. State governments throughout the United States have

adapted a strategy of shifting the poor onto Medicaid in order to shift the balance of payment to the federal government. Social service programs funded on a state level are being downsized or closed, but the federal government is resistant to sharing the burden of payment. While this war between the states and the federal government is waged, your clients suffer from lack of entitlement and from bureaucratic mismanagement. Where can they turn but to you? You must become their voice!

Personal Experiences with Advocacy

When I began providing services to People with AIDS, I learned immediately I would have to serve as an advocate for clients having difficulties with social service entitlements. One of the first issues I dealt with was the time frame for Social Security benefits. Some of my clients had to wait as long as three years from the date of application until benefits were awarded. Often, the client did not live long enough to realize his or her benefits. I knew that this was an injustice and wrote to my senator, Paul Simon, who was running for President at the time. The Senator agreed with me and forwarded my letter to the Director of Social Security, who also agreed. The system was changed. A position of ombudsman was created within the Social Security Administration and Social Security began a process of educating case managers about the nuances of the system.

My clients also had difficulties accessing basic health care. For instance, a major drug store chain in Chicago was offering flu-shots as a service to customers but refusing shots if an individual reported to the attending nurse that he or she was HIV-positive. I was asked to be a tester, that is, to go to one of the stores, report my HIV status, be refused services, and serve as a witness in litigation. I chose to call the chairman of the drug store chain and educate him about why this practice was discriminatory and would lead to a law suit and adverse publicity. The practice was changed within twenty-four hours.

As these kinds of situations have arisen over the years, I have become more and more comfortable with my advocacy role. I was intimidated the first time I called a congressional office, but I was surprised to find that the staff was open, friendly, and interested in helping. As I communicated with the staffs of elected officials, I was able to see that education was a two-way street. Elected officials who had been educated about the special needs of citizens could raise relevant issues during budget

hearings. I was also educated in turn by the staffs of elected officials so that I became more knowledgeable about the laws. As my own knowledge of the system grew, I was able to be more effective in providing accurate information to the client about possible pitfalls on the way to achieving entitlements. At the same time, I became more confident in dealing with applicable agencies. As my networking developed, I was able to streamline my advocacy by knowing who in an applicable office was most open to providing accurate information and direct assistance. I learned about the constituent services provided by members of congress and about the speed with which a letter to the appropriate representative or administrator can move the process along. I learned that, when my requests were initially denied, I could seek out additional information and develop a new action strategy.

Conclusion

Let me share with you the definition of discrimination that I have developed over the years that I have been privileged to work with People with AIDS. Discrimination is to do nothing when you can do something. Nothing versus something! What might something involve?

- Initiating a telephone call or a letter
- Providing an empathic ear
- Getting angry at injustice
- Fighting our own complacency
- Adding our voice
- Taking a client to an entitlement hearing
- Educating ourselves
- Becoming teachable by allowing our clients to teach
- Accepting the role of advocate as a central focus of our work

Advocacy serves as an effective manner in which to clear the board of solvable external problems so that effective counseling can begin. Advocacy clearly and strongly establishes our credentials as effective counselors, engages the client, and fosters a bond. Through advocacy, we help our current clients, empower these clients to help themselves and others, and thus enhance our effectiveness as practitioners and human beings.

John Cebuhar is an AIDS advocate in Chicago, Ill.